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# PALLIATIVE CARE IN RESIDENTIAL AGED CARE

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MAKING EVERY DAY COUNT

*Following a loved one receiving a diagnosis of a life-limiting illness, it may feel overwhelming to seek out support.*

*The WentWest Palliative Care in Residential Aged Care Handbook aims to assist you in accessing the support you need from diagnosis to the end-of-life period and beyond.*

*The handbook was developed as part of WentWest's End of Life and Palliative Care program, which aims to improve people's access to palliative care and enhance the quality of life and that of their loved ones. This handbook does not give professional advice and is not intended to be a substitute for professional advice. However, we hope the information compiled in this guide will enable you to make informed decisions, assist you with important conversations and access to the services you need in a timely manner.*

*The development of this directory was informed by the work undertaken by Murrumbidgee Primary Health Network, South Western Sydney Primary Health Network,, Palliative Care Australia, palliAGED, and CareSearch.*

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# What is Palliative Care?

The World Health Organization defines palliative care as: "...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering through early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Palliative care can assist with life-limiting diseases, including:

- Dementia, including Alzheimer's Disease and Vascular Dementia
- Advanced chronic lung disease
- Advanced heart disease, including heart failure
- End-stage kidney failure
- End-stage liver disease
- Cancer
- Degenerative neurological conditions
- Frailty, advanced age and/or multiple chronic medical conditions

Palliative care is not just end-of-life care but assists a person to live well with a life-limiting illness, ensuring that they have a good quality of life and are comfortable. Palliative care can be provided early in the course of a life-limiting illness, including treatments that aim to prolong life, such as chemotherapy or radiation therapy. A person may have palliative care when they first receive the diagnosis of a life-limiting illness or at other stages, depending on their needs. Palliative care supports pain and other symptom management, support to the family, and advance care planning.

Palliative care involves many health professionals, including, but not limited to:

1. Doctors
2. Nurses
3. Careworkers
4. Pharmacists
5. Physiotherapists
6. Speech therapists
7. Psychologists
8. Dietitians: help with nutritional problems
9. Spiritual/pastoral practitioners

For further information, visit Palliative Care Australia:

[LINK](#)

## Questions to Ask About Palliative Care (and Ask Often)

It is common to feel overwhelmed when you are told that your loved one has a life-limiting illness or when a referral to palliative care is discussed. Below are some questions that can help you to get the information you may need.

### Questions to consider asking your family member's residential aged care facility:

1. My family member is not approaching the last days of my life, so why are you talking to me about palliative care now?
2. How will palliative care help my family member?
3. Are you able to provide a palliative approach to care?
4. What palliative care training do your staff receive?
5. If my family member needs equipment to help with comfort, will the facility provide it?
6. Will my family member be able to receive specialist palliative care if they need it?
7. How will staff recognise when my family member is close to dying, and what processes are in place for this?
8. What support will I have when my family member is close to dying?
9. How do I tell others what is happening to my family member?
10. Who can support me in my grief?
11. Who can I speak to about my family member's spiritual and emotional needs?

### Questions to consider asking your family member's doctor:

1. What is the name of my family member's condition/s?
2. How much longer is my family member likely to live?
3. What can I expect in the last months, weeks and days of my family member's life?
4. What symptoms can I expect, and how will this be managed? How can pain be managed?
5. What treatments will my family member continue to have? What is the purpose of those treatments? Does this treatment aim to help my family member live longer or control their symptoms? Are there any side effects of the treatment?



# Advance Care Planning

Advance care planning is the process of discussing and planning for a person's future health care needs with their loved ones and with their health care team. Advance care planning allows a person to talk about their values, beliefs and preferences and be able to determine the treatments they wish to have. Advance care planning is an ongoing process as these preferences may change as the person's life changes or encounters different stages of their illness.

Advance Care Directives is a document in which a person states their values, wishes and preferences and specifies the types of medical or health care treatments that they wish to have or do not wish to have. Advance care planning means that a person's loved ones and their health care team can make decisions about the health care they receive based on their stated preferences when they are not able to communicate these themselves. Your family member's residential aged care facility will be able to assist you with information on how your family member can complete an advance care directive.

Advance Care Planning Australia provides advice, information and support to people interested in advance care planning. You can call Advance Care Planning Australia's free National Advance Care Planning Support Service™ on 1300 208 583 for information and assistance with advance care planning. Further information can be found at:

[LINK](#)

There may be times when a person is not able to make decisions for themselves about their health care or other aspects of their lives. This may be due to an acute illness, such as delirium, or a chronic illness, such as dementia. People having trouble with their thinking or cognition may need additional support with decision-making. Your family member's doctors and residential aged care facility provider can assist you if you have concerns about your family member's decision-making.

If there is concern about your family member's decision-making and you need to provide support for them to be able to make decisions or need to make decisions on their behalf, consider the following:

- Ensure that your family member is included in discussions about their care and health.
- Does your family member have an advance care directive, or have they provided verbal instructions regarding their wishes?
- If your family member has not provided instructions, consider what they would decide if they could make this decision. Consider their wishes, values and beliefs, including cultural and spiritual beliefs and practices.
- If you are unclear as to what decision your family member would have made, consider what is in their best interest. Ensure that you ask any questions you need to so that you can fully understand the situation and any benefits and risks of the available options. You should refuse health care likely to result in an outcome your family member would want to avoid.
- When doctors and health professionals provide you with information, it can help to summarise what you think they mean. Start by saying, 'So if I've got that right, you mean.....' or 'So what you are telling me is that....'
- Be prepared to advocate for your family member if you feel that proposed medical treatments are not what they would have wanted or will impact too negatively on their quality of life.
- Speak with family or friends for support and guidance.
- Ask your family member's GP, specialist or residential aged care facility for support.
- Sometimes family members disagree with care directives or decisions. Families are not always close, and there may be general communication problems. If this happens to you, talk to the residential aged care staff about a family meeting to talk about what is happening.

Further information can be found at Dementia Australia:

[LINK](#)

# Living with a Life-Limiting Illness

When someone has a life-limiting illness, the length of time they have left to live can vary. Some people will live with their condition for many months or years, such as dementia. Other people may have a very short period of time from diagnosis to death and may have only weeks to live. Sometimes the progress of a person's illness will vary with periods where the person feels well, and then experience more symptoms. These cycles may continue through the course of the disease.

When a person is seriously ill, changes may occur in all parts of their life, such as the person losing their appetite, changes in their walking or independence, and changes in their mood or energy levels.

A symptom is a physical or mental characteristic of a disease or illness that a person experiences. These often vary from person to person and may be mild or more severe. Common symptoms experienced by someone with a life-limiting illness include:

- Anorexia - poor appetite
- Anxiety - when a person feels scared or worried about something, and these feelings do not go away
- Dysphagia - difficulty swallowing, commonly occurs in dementia
- Dyspnoea - trouble breathing or breathlessness
- Fatigue – tiredness
- Nausea - feeling that you want to vomit

Ask your family member's GP, specialist, or residential aged care facility provider about any symptoms that your family member has and the strategies that can be used to manage these.

## Things to Consider

- Spend time with your family member and be open to listening to them
- Be prepared to listen to your family member talk about their condition
- Show warmth and concern
- Ensure you look after yourself during this time, as it can be tiring and stressful

## Special Considerations: A Person Living with Dementia

If your family member is living with dementia, there may be other considerations to make. People living with dementia can find it challenging to express emotions, understand what is said to them, and may not be able to communicate their thoughts. This can cause the person distress and may worry you. Some techniques to consider include:

- Remain calm and avoid arguing or correcting words
- Speak slowly and clearly, keeping sentences short
- Sit with your family member rather than standing over them
- Avoid negative body language
- Use touch, such as holding hands or a hug, as your family member is comfortable
- Consider reminiscing with your family member - looking at old photographs or listening to music can help with this



A person living with dementia will have changing needs as the dementia progresses. In the later stages of dementia, a person may need a lot of physical care as they lose the ability to undertake tasks such as walking, feeding themselves and washing and dressing. The person may eventually be unable to walk altogether and need to be in bed or a chair all the time. A person living with dementia in the later stages may forget how to eat or drink or may forget how to swallow food or drink. The person may also have a decline in their memory and have difficulties recognising loved ones. They may also have difficulties communicating their thoughts and find it challenging to understand what is going on around them. These challenges can be very distressing for a person's family and friends. Some things to consider when your family member is experiencing these issues include:

- Continue to communicate with your family member who has later-stage dementia. People can respond to touch and sound even if they cannot verbalise their feelings or thoughts.
- If you are worried about your family member's eating or drinking, talk to their GP or residential aged care provider for guidance.
- People living with later-stage dementia can still experience pleasure and joy. Consider ways to provide opportunities for pleasure and joy for your family member, such as bringing in flowers or providing someone who loves to knit with wool to handle.

For further information, counselling or support, call the Dementia Australia National Dementia Helpline on 1800 100 500 or visit the Dementia Australia website:

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# End Of Life

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As someone approaches the last days or weeks of life, they often have signs common to people at the end of life. They include:

- Day to day, the person may deteriorate, and this happens quickly and is not able to be reversed.
- The person may be restless or agitated, or the person may be difficult to wake up. This may also change over the course of the day or week.
- The person may develop acute confusion, called delirium, which is not due to an acute illness.
- The person may become weaker and need more assistance with their day-to-day activities.
- The person may not have much appetite or be interested in drinking fluids. The person may experience weight loss which worsens over time and does not get better.
- The person may have difficulties with swallowing.
- The person's breathing may change or may become noisy. The person may have secretions in their upper airway, which they cannot cough out.
- The person may have cool hands and feet.

## Things to Consider

- Talk to your family member's GP, specialist and residential aged care provider if you have any questions about your family member's symptoms or other aspects of care.
- You should discuss with your family member's residential aged care provider what needs to be done after death. It may help if you have a list of things to do, with names and phone numbers. Consider who you will want to phone.
- When your family member dies, you may want to spend time with them. Speak with the residential aged care provider about this.
- Consider which funeral director you want to use and keep their details handy.



# Counselling and Support for Grief and Bereavement

Many people are quite shocked by the death of a family member, even when it was expected. Everyone grieves differently, and there is no correct way of grieving. Some people find they remain in shock for weeks following the death, and it may take a long time to recover. Seek support from friends and family members and talk about your family member with them.

Following a death, you may spend time remembering the person's life and their stories and connection to you. There are many ways you could do this, such as a remembrance service or celebration of life or a memory box or scrapbook.

If you need support with grief and bereavement, the services below can assist you:

## Western Sydney Local Health District Bereavement Counselling Service

Bereavement counselling is available if you would like to access it. Not everyone needs or wants this service. Bereavement counselling can assist you with expressing your grief, understanding your needs, and adjusting to a changed life. Not everyone wants or needs bereavement counselling. For further information, call (02) 9881 1723 or email: [WSLHD-BereavementCounselling@health.nsw.gov.au](mailto:WSLHD-BereavementCounselling@health.nsw.gov.au)

[LINK](#)

## Lifeline Counselling

Lifeline provides 24-hour phone crisis support and counselling and face-to-face counselling for bereavement and financial crises. Call 13 11 14; the line is available 24 hours per day. For further information, visit:

[LINK](#)

## GriefLine

GriefLine is a national not-for-profit organisation that provides free telephone support, online bereavement support groups and forums, grief resources and information and education and training programs. Call their Helpline on 1300 845 745 Monday to Friday from 8am to 8pm. For further information, visit:

[LINK](#)

## Cancer Council's Information and Support Line

The Cancer Council's Information and Support Line provides expert advice and support by health professionals to people living with cancer, their family, friends, workplaces and health care professionals. For further information, call 13 11 20 or visit:

[LINK](#)

## Solace NSW

Bereavement support group run in the Hills Shire. Contact Kenneth Sutherland at (02) 9519 2820 or via email at [SolaceNSW@gmail.com](mailto:SolaceNSW@gmail.com). For further information, visit:

[LINK](#)

## Mental Health Access Line

1800 011 511 is NSW Health's 24/7 state-wide free phone service which links people with NSW Health mental health services.

It is staffed by trained mental health professionals who offer mental health advice, complete a brief assessment and make recommendations for appropriate care, including referral to NSW Health mental health services. For further information, call 1800 011 511 or visit:

[LINK](#)

## Other services

WentWest commissions mental health services across a range of needs. For further information, visit:

[LINK](#)

## Other Support

### Australian Death Notification Service

The Australian Death Notification Service is a free government initiative to notify multiple organisations that a person has died using a single online notification. Call 13 77 88 Monday to Friday, 7am to 7pm or email [adns.bdm@customerservice.nsw.gov](mailto:adns.bdm@customerservice.nsw.gov). For further information, visit:

[LINK](#)

### End of Life Planner

The NSW Government has developed an End of Life Planner kit. Planning ahead for the end of life will ensure that your affairs are managed as you want them to be if you lose your capacity to decide for yourself or if you die. The planner will not provide you with finalised legal documents, but it will help you before meeting with a professional advisor or solicitor by breaking down what is required for the legal documents.

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### Gather My Crew

Gather My Crew assists people who are experiencing a crisis by coordinating assistance from family and other support people via an app. For further information, visit:

[LINK](#)

# Aged Care Advocacy Services

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## Older Persons Advocacy Network

The Older Persons Advocacy Network (OPAN) offers free, independent and confidential support and information to older people seeking or already using Australian Government funded aged care services across the country, along with their families and carers. For support, contact OPAN on 1800 700 600 or visit:

[LINK](#)

# Palliative Care Supports for First Nations People

## Advance Care Planning Australia

### Video: Taking Care of Dying Time

Aboriginal Community Support Worker, Chris Thorne, talks about the importance of writing down an advance care plan so people will know your wishes if you become seriously ill or injured and cannot speak for yourself. For more information, visit:

[LINK](#)

Companion booklet: **Taking Control of Your Health Journey** available at:

[LINK](#)

## 13YARN

A 24 hour, seven days a week phone line to support First Nations people going through a hard time. Individuals can connect to an Aboriginal or Torres Strait Islander Crisis Supporter to have a yarn if they are feeling worried. For more information, call 13 92 76 or visit:

[LINK](#)

## The Victorian Aboriginal Community Controlled Health Organisation

The Victorian Aboriginal Community Controlled Health Organisation's - *Understanding the Palliative Care Journey: A guide for individuals, carers, communities and family* - provides information to aid in understanding what a palliative care journey may hold for First Nations people.

[LINK](#)

## Palliative Care Australia

Palliative Care Australia developed resources for First Nations people in partnership with the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives, Australian Indigenous Doctors Association and Indigenous Allied Health Australia and others. For further information, visit:

[LINK](#)

## The Aboriginal Health and Medical Research Council of NSW

The Aboriginal Health and Medical Research Council of NSW has created a toolkit to guide First Nations people through end-of-life care. For further information, visit:

[LINK](#)

## Caring for Spirit

Caring for Spirit aims to provide a centralised online source of appropriate resources and information related to dementia and aged care for First Nations communities. For further information, visit:

[LINK](#)





# Support for Culturally and Linguistically Diverse Communities

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## Advance Care Planning Australia

Access to translated resources for people and their families about advance care planning. For further information, visit:

[LINK](#)

## Palliative Care Australia

Multilingual resources for people and their families about Palliative Care. For further information, visit:

[LINK](#)

## CarerHelp

CarerHelp brings together a range of pathways, tools, videos and information to support carers during the end-of-life process, including translated materials. For more information, email [carerhelp@flinders.edu.au](mailto:carerhelp@flinders.edu.au) or visit:

[LINK](#)

## STARTTS

Refugees often experience multiple levels of trauma, which impact all areas of their life and community. In recognition of this, STARTTS provides a holistic range of services which include counselling, group work and other support. For further information, call (02) 9646 6700 or visit:

[LINK](#)

## SydWest Multicultural Services

SydWest Multicultural Services provides a range of services for refugees and migrants in Western Sydney. For further information, call (02) 9621 6633 or visit:

[LINK](#)

## Translating and Interpreting Service (TIS National)

The Translating and Interpreting Service (TIS National) provides interpreting services to people who do not speak English and to agencies and businesses that need to communicate with their non-English speaking clients. These services enable non-English speakers to independently access services and information in Australia. TIS National contract more than 2600 interpreters across Australia in more than 150 different languages. Non-English speakers can access immediate telephone interpreters through TIS National by calling 131 450.

# Podcasts/TED Talks/Videos/Books

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## Video: Advance Care Planning Australia: Love is Not Enough

How well do you know your partner? We put couples to the test. You know their favourite food. You're pretty sure about their bucket list holiday destination. But are you prepared for life's most challenging decisions?

[LINK](#)

## TED Talk: Lucy Kalanithi: What Makes Life Worth Living

In this deeply moving talk, Lucy Kalanithi reflects on life and purpose, sharing the story of her late husband, Paul, a young neurosurgeon who turned to writing after his terminal cancer diagnosis. "Engaging in the full range of experience -- living and dying, love and loss -- is what we get to do," Kalanithi says. "Being human doesn't happen despite suffering -- it happens within it."

[LINK](#)

## TED Talk: Peter Saul: Let's Talk About Dying

We can't control if we'll die, but we can "occupy death," in the words of emergency doctor, Peter Saul. He asks us to think about the end of our lives and to question the modern model of slow, intubated death in a hospital. Two big questions can help you start this tough conversation.

[LINK](#)

## Podcast: Palliative Care Australia: Thursdays@3: Life, Death and Music

Thursdays@3 is a podcast and video series from Palliative Care Australia, featuring discussions with experts from the field and people living and working at the end of life. With over 40 years of experience in nursing, Rose Sexton has seen a thing or two! Her passion for palliative and end-of-life care emerged early, with an active interest in Oncology nursing. Alongside these health-related passions, she is, at heart, a musician and actress. Rose has also had personal experience caring for her husband through his end-of-life journey in 2019.

[LINK](#)

## Books

- Tuesdays with Morrie by Mitch Albom
- Being Mortal by Atul Gawande
- When Breath Becomes Air by Paul Kalanithi
- The Lovely Bones by Alice Sebold
- The Book Thief by Markus Zusak





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